DOCUMENT RESUME

ED 309 599 EC 220 590

AUTHOR Look, Kathy
TITLE Tourette Syndrome.
PUB DATE 8 Dec 88
NOTE 16p.
PUB TYPE Reports - Descriptive (141) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Classroom Techniques; *Clinical Diagnosis; *Developmental Disabilities; Elementary Secondary Education; Etiology; *Teaching Methods; *Therapy
IDENTIFIERS *Tourette Syndrome

ABSTRACT

Tourette Syndrome has a history of being misdiagnosed or undiagnosed due to its unusual and complex symptoms. This paper describes: the symptoms of Tourette Syndrome; its etiology; age of onset; therapeutic methods, such as drug therapy, psychotherapy, diet control, and hypnosis; educational implications; and employment prospects. Several suggestions are outlined for teachers to use in working with students with Tourette Syndrome, focusing on stress avoidance, oral testing, resource room use for math study, motor problems, and improvement of self-image and peer relations. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED309599

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

TOURETTE SYNDROME

Kathy Look
Northeastern University
125 S.O'Plaine
Gurnee, IL 60031
(312) 249-4309
December 8, 1988

EC 220590

BEST COPY AVAILABLE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Kathy Look

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Tourette Syndrome, also known as Gilles de la Tourette Syndrome in medical books, is a neurological disorder. It has a history of being misdiagnosed or undiagnosed due to its unusual and complex symptoms. These symptoms are: "multiple, purposeless, involuntary, rapid, repetitive muscular movements of the face, head, and/or body and limbs, as well as involuntary noises and vocalizations." (Tourette Syndrome Association, 1981). The operant word in this description is INVOLUNTARY. There is a loss of inhibitory control. "The great majority of Tourette Syndrome patients who are old enough to describe their own emotional climate will speak of a feeling of 'inner tension' which is almost continually present. They describe a longing for the ability to relax 'like other people'. The release of the tic will bring at least a momentary release of this tension." (Bruun, 1984). In some cases, the more a Tourette Syndrome sufferer tries to suppress the symptoms, the more he/she is inclined to have an outburst. However, when the Tourette Syndrome sufferers voluntarily suppresses the symptoms for a short time, they eventually reappear. A Tourette Syndrome sufferer may eliminate shrieking, but eventually substitute another symptom in its place. Tourette Syndrome sufferers do not exhibit symptoms in their sleep. During particularly absorbing activities or times of deep concentration the symptoms subside. The outbursts can be characterized by one or more of the following: shrieking, clicking, spitting, throat clearing, barking, yelping, grunting, sniffing, coughing, cursing, making facial grimaces, screaming, and producing muscular tics. Confused parents of Tourette Syndrome sufferers are told to seek psychological advice for the symptoms. All too often, the initial diagnosis is that the problem has a psychological rather than physiological basis, or the symptoms are not diagnosed at all. All the symptoms are exacerbated by stress. "The tendency of the disorder to wax and wane over time, and for the repetoire of symptoms to change makes long term evaluation of treatment difficult." (Golden & Hood, 1982).

What causes Tourette Syndrome? The exact cause is unknown. The United States Department of Health and Human Services (1980) states that Tourette Syndrome is thought to be a chemical abnormality in the neurotransmitter system by which the brain regulates movement and behavior. Neurotransmitters are the chemical transmitters that carry signals from one cell to another in the brain and along the nerves. It is evident that Tourette Syndrome is hereditary. It appears more than one member in the family can suffer from Tourette Syndrome. Tourette Syndrome crosses ethnic and socioeconomic boundaries. The course of the disorder is not degenerative, nor terminal. It is life long, however, and although one may have periods of remission, there is no cure. Tourette Syndrome sufferers frequently exhibit abnormal EEG and minimal brain dysfunction. There is a 3:1 male to female ratio among people who have Tourette Syndrome.

According to the DSM-III (1980), the disorder may appear as early as two years of age and almost always appears before the age of thirteen. Incidence is not known, due to a very large percentage of sufferers who are not diagnosed by family doctors. This may be due to the fact that pediatricians and family doctors are unfamiliar with the disorder. Mild to moderate cases are frequently overlooked by doctors. The Tourette Syndrome Association is trying to overcome this problem in two ways. The Tourette Syndrome Association has written a pamphlet solely for the education of family physicians, including pediatricians. The Tourette Syndrome Association also offers a referral list of doctors who are familiar with the disorder. The hope is to improve the accuracy of diagnosis and the understanding of Tourette Syndrome.

Once a person has been diagnosed as having Tourette Syndrome, it is necessary to understand the educational implications. "Tourette Syndrome is a Developmental Disability that meets the criteria setforth in PL 95-602, Developmental Assistance and Bill of Rights Act, U.S. Congress, 1978." (Governor's Planning Council on

Developmental Disabilities). Language is affected by Tourette Syndrome. Speech can be interrupted by numerous characteristics of the disorder; i.e., sniffing, grunting. Vocalized trains of thought are disrupted by repeating one's own words or other's words (echolalia), blocking (stopping in midsentence and starting over) and/or involuntary use of obscenity (coprophilia).

Attention Deficit Disorder (ADD) is a common problem associated with Tourette Syndrome. It is difficult to know whether the learning problems are caused by the Tourette Syndrome or by the Attention Deficit Disorder. Trying to sit in a classroom while struggling to suppress the Tourette Syndrome symptoms will definitely interfere with classroom work. The results is poor performance. These attempts at suppression mean more concentration and energy is being placed on non-educational endeavors. Thus it takes a Tourette Syndrome sufferer more time to do less work. For example, one Tourette Syndrome sufferer said it took him three hours to read ten pages. It is easy to see why 60% of people with Tourette Syndrome have learning disabilities. Perceptual problems appear during infancy or early childhood. Cognitive dysfunction associated with processing information into memory is evident.

Every Tourette Syndrome case is different and it is important not to make too many generalizations. However, a teacher can do some basic things to help a Tourette Syndrome sufferer work effectively in the classroom. The National Tourette Syndrome Association (NSTA) recognizes the following suggestions to be considered in an Individual Education Plan (IEP):

1. Stress always worsens the Tourette Syndrome sufferer's symptoms. A teacher is obliged to do whatever is necessary to reduce that stress. Do not give a time limit on a test. Do not exhibit frustration toward a Tourette Syndrome sufferer or his/her peers due to a symptom.

2. Decrease the possibility of peers teasing the Tourette Syndrome sufferer. The National Tourette Syndrome Association suggests a teacher or teacher's aide should be assigned to stay within 20 feet of him/her at all times.

3. Some children with Tourette Syndrome have poor handwriting. Further, they may not be able to translate their knowledge through writing. Allow for oral testing if necessary or some other alternate form; i.e., tape recording, peers giving copies of notes.

4. Some children have difficulty with math. If a Tourette Syndrome sufferer has below grade level math skills, a resource room for improvement of math skills should be provided.

5. Some children have difficulty reading quickly because they blank out on words or sentences. This is called Blocking. A teacher can assist a student by using a tape recording to take readings that are difficult.

6. A Tourette Syndrome sufferer needs to be allowed the freedom of leaving the room, should he/she need to discharge symptoms. The teacher assigns a designated "safe place" for the child to go.

7. A Tourette Syndrome sufferer has much stress and a low self-image due to the symptoms of this syndrome. Psychological counseling may be needed in order to help the child deal with his/her condition. A teacher needs to build up the Tourette Syndrome sufferer's confidence by giving positive feedback

and by not criticizing or loosing patience with any of the Tourette Syndrome sufferer's symptoms.

A teacher should use caution when interpreting I.Q. scores. Tourette Syndrome sufferers score lower than average on these tests, but this is not an accurate account of a child's capabilities. Tourette Syndrome sufferers have difficulty demonstrating what they know, so they do poorly on formal testing. This is also true of group achievement tests. In general, a student's academic performance does not match his/her intellectual capabilities. Teachers can help compensate for this low scoring by giving unrestricted time to complete a test. The teacher simply notes in written form that time allowance has been given due to a confirmed diagnosis of a developmental disability.

About 50% of the patients diagnosed as having Tourette Syndrome have hyperactivity, short attention span, and difficulty with concentration. In many cases, a child is first diagnosed as having Attention Deficit Disorder (ADD) and given drugs to treat it. These drugs can make the tics and noises worsen. In addition, before a child is diagnosed as having Tourette Syndrome he/she is considered a disturbance in the classroom. All the symptoms associated with Tourette Syndrome might be considered attention seeking or disruptive in the classroom and cause for special education without the knowledge of the correct diagnosis. It takes the combined skill of trained doctors, educational professionals, and the knowledgeable parent to diagnosis and treat the child.

If a Tourette Syndrome sufferer has had bad experiences with teachers, administrators, or peers, he/she may become tramatized by the educational system. The new behavior disorder of school refusal may occur. In addition to learning to deal with the complicated symptoms of Tourette Syndrome, the sufferer now has to deal with the symptoms of school phobia. DSM-III diagnosis of school phobia is the persistent irrational fear and compelling desire to avoid school. Parents and

education professionals again must work to reverse this new problem, while simultaneously working with the Tourette Syndrome sufferer to cope with the symptoms of Tourette Syndrome. Early diagnosis of Tourette Syndrome would prevent the secondary problem of school phobia. Early diagnosis is also crucial in the management of Tourette Syndrome in school. The sooner the diagnosis, the sooner parents and school can work to facilitate the needs of the child.

The Tourette Syndrome Association highly recommends that children who have Tourette Syndrome remain in the classroom. Too often, the Tourette Syndrome sufferer has been isolated from peers, and is unable to establish social relationships. This inability during the development years causes great stress during adulthood when the Tourette Syndrome sufferer is seeking employment and continues to have difficulty in social situations.

There are social and psychological implications associated with Tourette Syndrome that need to be addressed. Some Tourette Syndrome sufferers have leg tics that cause them to trip or fall. Mobility also becomes a problem when Tourette Syndrome sufferers elect to stay at home rather than face the embarrassment of stares and commentaries about the symptoms. Some Tourette Syndrome sufferers even have difficulty obtaining a driver's license.

Tourette Syndrome sufferers have the perception, both real and imagined, that people will reject them. Too often they are subjected to insults, harassment, rebuff and abuse. It becomes difficult to establish relationships with peers. Loneliness and alienation become prevalent. The psychological implications are evident. The more withdrawn a Tourette Syndrome sufferer becomes, the more peers ostracize him/her. Untrained teachers, as well as other adults, may even harass the Tourette Syndrome sufferer so that he/she feels there simply is no help or support.

This isolation and the inability to control one's symptoms leads to depression. The depression leads to stress which, in turn, can cause more symptoms. This, in turn, causes more feelings of depression and hopelessness. This depression must be addressed by a social worker or counselor. Left unassisted by some type of support program, a Tourette Syndrome sufferer's frustration with his/her quality of life can lead him/her to choose suicide. A Tourette Syndrome sufferer feels that suicide is better than the "no life" of daily living that is characterized by rejection and harassment by others and poor self-esteem.

The Tourette Syndrome sufferer cannot control simple motorial movements, at least for long periods of time. Often, this is translated into the inability to control one's own destiny. Hopelessness and despair becomes so prevalent that the Tourette Syndrome sufferer feels no self-motivation or self-direction. Some tasks (like shopping and riding a bus), or entertainment (like going to the movies and going to a museum) become an exercise of torment. Some Tourette Syndrome sufferers prefer not to venture out of the home, rather than suffer the humiliation of taunting or staring. This eventually leads to no motivation to interact with society. This is a devastating psychological problem.

Tourette Syndrome sufferers continue to have difficulties into adulthood. The first obstacle is employment. Tourette Syndrome sufferers have difficulty obtaining and maintaining a job. Vocalization symptoms make employment whereby a Tourette Syndrome sufferer must use the phone or deal with public an impossibility. In addition, many people perceive Tourette Syndrome sufferers to be incapable of carrying out tasks. This attitude barrier of potential employers must be overcome. As stated earlier, symptoms of Tourette Syndrome are not always constant. A Tourette Syndrome sufferer may have one set of symptoms at one point and some time later he/she has another set of symptoms. This can make steady employment difficult. A person with Tourette Syndrome may exhibit leg and vocal tics, enabling

him/her to obtain a job as a bookkeeper. Three months into the job the person with Tourette Syndrome begins to exhibit arm tics, causing the inability to add figures correctly. "It is wise to ask the person with Tourette Syndrome just how variable his symptoms have been during the last years." (Tourette Syndrome Association).

Tourette Syndrome Association suggests that Tourette Syndrome sufferers begin employment in jobs that offer the least amount of socialization with the uneducated public or a job whereby vocalization symptoms will go unnoticed. For example, kitchen or factory work. However, Tourette Syndrome Association also notes that generalizations are not always appropriate, because each Tourette Syndrome sufferer is different. To make this point, the Tourette Syndrome Association of New York reports that in its membership, as Tourette Syndrome sufferers, are lawyers, doctors, engineers, chemists, show business and other visible careers (Tourette Syndrome Association).

The most common treatment for Tourette Syndrome is pharmacodical. The most often used medications are halo-like drugs. Haloperidol being the most often used. It was first used in 1961 with good success. However, much caution is used before medication is given. Doctors prescribe medication only when symptoms interfere with daily living, psychologically and socially. If a Tourette Syndrome sufferer has mild symptoms and has adapted well socially and psychologically, medication will probably not be prescribed.

Although haloperidol is effective, it can be difficult to use because of its numerous side effects. These side effects can be as difficult as the Tourette Syndrome symptoms and need medication themselves to be alleviated. The side effects are as follows:

1. Motor difficulties: tremors, slowed movements, increased muscle tone, abnormal gait when walking, drooling. A medication called benztropine is given to counter these side effects.

2. Akathisia: Characterized by restlessness or a need to pace. Benztropine is also used to counter this side effect, however, it does not always alleviate it.

3. Tardine dyskinesia: grimacing of the mouth and generalized jerkiness of the body parts.

4. Drowsiness: this side effect is countered by advising patient to consume caffeine products. With some patients, the drowsiness is also accompanied by irritability.

5. Depression: characterized by unexplainable sadness, loss of meaningfulness, decreased energy and tearfulness (Caine, M.D.).

6. Appetite gain: some patients, particularly children, develop a gain of appetite resulting in increase in food intake. If this intake of food is not curtailed, weight gain of 50-60 pounds is not uncommon. In today's weight-aware society, this side effect has more significance than doctors may realize.

7. Cognitive impairment: students using haloperidol, begin to have lower grades and difficulty understanding and retaining new material. Lack of motivation occurs.

8. Dry mouth: which is easily corrected by more liquid intake.

9. Nasal congestion.

10. Sensitivity to sunlight: which is easily corrected by sunglasses.

11. Loss of near-sided vision: which can only be corrected by eye-glasses.

12. Constipation: corrected by laxatives.

After examining closely all the side effects of haloperidol, it can easily be seen why the use of the drugs is done with such caution. The dosage for each patient is monitored and regulated carefully. The intent is to reduce the dosage to the least amount possible while maintaining sufficient haloperidol in the blood system to alleviate the Tourette Syndrome symptoms. An additional difficulty is that each patient absorbs the medication differently. Although there are common prescribed dosages, the doctor must prescribe dosages based on each individual patient's ability to absorb the drug. Regular monitoring is also needed due to the ever changing nature of Tourette Syndrome symptoms. The goal of haloperidol treatment is to lessen Tourette Syndrome symptoms to a level whereby patients themselves can manage them in daily living. Many patients are able to suppress the Touretts Syndrome symptoms while at school or in public, but then need to release the penned up symptoms in a safe environment, home.

Other medications have had reported effectiveness for the relief of Tourette Syndrome symptoms. These drugs are Pimozide, Penfluriodol, and most recently, Clonidine. However, more research needs to be done to examine more closely the possible side effects.

Medication affects the physical symptoms of Tourette Syndrome but it does not affect the secondary problems and complications that occur. Treatment of these problems is dependent on how well a Tourette Syndrome sufferer deals with the syndrome as a whole and how supportive family, school and peers are. Because of the importance of support from others, family counseling and supportive psychotherapy are recommended. The goal here is that the Tourette Syndrome sufferer accept his/her condition, learn to manage the symptoms as they arise, and not let the symptoms disable him/her to the point that they cannot function in society. In addition, the family learns to accept the Tourette Syndrome sufferer as he/she is and learns to support and listen to the special needs of the Tourette Syndrome sufferer.

The family counselor should be someone who is expertly knowledgeable about Tourette Syndrome and its problems. The therapy should take into account the age of the Tourette Syndrome sufferer as well as the unique impact Tourette Syndrome has on the individual sufferer. Therefore, the type of therapy can range from play therapy in the very young to rap sessions, where teenagers can talk about feelings and reactions of the condition. "Communication may be the key to helping the child cope." (Parker, 1985). All members of the family, including siblings, should be encouraged to participate in therapy.

Although the best known approach in dealing with Tourette Syndrome is to combine Pharmacotherapy and some form of psychotherapy, there are a few alternate forms of treatment that show promising results which should be examined. However, these therapies are new and experimental. There are no rigorous scientific studies to support evidence of cure or reduction of symptoms. However, there are anecdotal reports. Enthusiastic and supportive parents are interested in broadening the field of Tourette Syndrome therapy. Nutrition and diet control is one of the alternate therapies that is being explored. Nutrition has been shown to be beneficial in helping hyperactivity and Attention Deficit difficulties. The Tourette Syndrome Association feels more money should be spent and more research should be conducted to see what further implications can be made linking nutrition to the reduction of Tourette Syndrome symptoms.

Another alternate therapy used in conjunction with medicine and psychotherapy is hypnosis. The rationale here is that a Tourette Syndrome sufferer's stress greatly affects the manifestation of symptoms. If a Tourette Syndrome sufferer can find an active way of relieving stress, he/she can have better control of the symptoms. First the hypnotist relaxes the Tourette Syndrome sufferer during sessions. The eventual aim it to teach Tourette Syndrome sufferers to learn self-hypnosis procedures themselves. Another way of possibly using hypnosis to help

Tourette Syndrome sufferers is to give a hypnotic suggestion that reduces the severity of symptoms. For example: A boy with Tourette Syndrome exhibits the symptom of scratching his arm so hard it bleeds. A hypnotist could give the suggestion that whenever the boy involuntarily begins to scratch the arm, he will instead stroke or touch the arm lightly. The Tourette Syndrome symptom occurs, the urge is still there, but its severity has been greatly reduced. Again, this therapy needs more rigorous scientific research to support it.

The course of Tourette Syndrome varies from mild to severe between individual sufferers. The symptoms are ever changing, waxing and waning. The degree of intrusion Tourette Syndrome has on a person's life is determined by that person's personality and ability to cope. However, in general, it can be said that Tourette Syndrome itself is not infectious, terminal, or debilitating. If a Tourette Syndrome sufferer can accept the condition, has the support of family and friends and has high self-esteem, the chances are greater for a more normal and social life. It is common for the symptoms to decrease in a person's mid-twenties. Great difficulties must be overcome; and a Tourette Syndrome sufferer can do it with help, understanding, and support and become an active, productive person in society, even a lawyer, doctor, or entertainer.

REFERENCES

Governor's Planning Council on Developmental Disabilities, Springfield, Ill., 1979. Excerpts of definition distributed by Tourette Syndrome Association, Inc., Skokie, Ill.

Rosa A. Hagin, Phd., Ronnie Beecher, Phd., Henrietta Kreeger, M.A. Gary Pagona, M.D., "Guidelines for the Education of Children with Tourette Syndrome" (paper given at the Annual Meeting of the American Psychological Association, Montreal, Quebec, Canada, September 4, 1980.

Abbey Meyers, "Employment of People with Tourette Syndrome (New York: Tourette Syndrome Association, Inc.).

Eric D. Caine, M.D., "The Pharmacotherapy of Tourette Syndrome", New York: Tourette Syndrome Association, Inc.

Karen Parker, "Helping School-Age Children Cope with Tourette Syndrome." Journal of School Health., Vol. SS, (Jan. 1985) 30-32.

American Psychiatric Association, The Diagnostic and Statistical Manual of Mental Disorders. 3rded. Washington, D.C.: APA, 1980.

A. K. Shapiro and E. Shapiro. Controlled Study of Pimozide vs. Placebo in Tourette Syndrome. Am. J. Child Psychiatry. 1984. 23: 161-173.

Anne M. Bauer and Thomas M. Shea; "Tourette Syndrome: A Review & Educational Implications" Journal of Autism & Developmental Disorders, V. 14, (March 1984).

Tourette Syndrome Association, Tourette Syndrome and Tourette Syndrome Association: A Summary New York: Tourette Syndrome Association, Inc., 1981.

Ruth Dowling Bruun, M.D., "Gilles de la Tourette Syndrome: An Overview of Clinical Experience" Journal of the American Academy of Child Psychiatry, 23, (1984): 126-133.

Gerald S. Golden, M.D.; and O.J. Hood, M.D., "Symposium on Persistent Signs & Symptoms: :Tics & Tremors" Pediatric Clinics of North America, Vol. 29, (Feb. 1982): 95-103.

U. S. Department of Health & Human Services: Office of Scientific & Health Reports, Fact Sheet: Tourette Syndrome, Bethesda, Maryland: National Institute of Health, September, 1980.

A. K. Shapiro and E. Shapiro, "Tic, Tourette Syndrome and Other Movement Disorders: A Physician's Guide." Bayside, New York: Tourette Syndrome Association, 1980.

J. Wertheim, Coping with Tourette Syndrome in the Classroom. New York: Tourette Syndrome Association, 1979.